A VISION FOR HEPATITIS C

the hepatitis C coalition

test
treat
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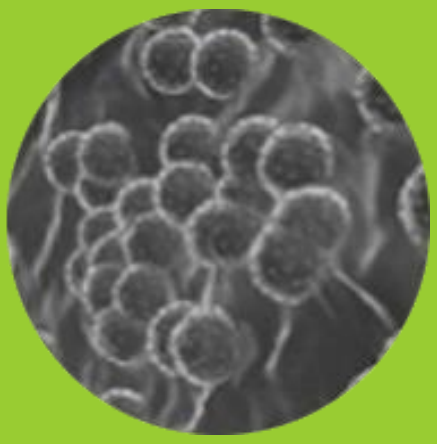

The Hepatitis C Coalition is a group of leading clinicians, patient organisations and other interested parties committed to the reduction of morbidity and mortality associated with Hepatitis C and its eventual elimination. The Coalition is run with funding from Gilead Sciences Ltd.

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A VISION FOR HEPATITIS C: TEST, TREAT, CURE

Our plan for change

The Hepatitis C Coalition has established eight calls for tackling hepatitis C. We need everyone to play their part in eliminating the virus.

There is an unprecedented opportunity to improve services and outcomes for people with the virus significantly. The new NHS and public health commissioning environments can be used to drive improvements and, if advances in cost-effective treatments are matched by improvements in service delivery, the elimination of hepatitis C from the UK is achievable.

Seizing this opportunity requires strong national leadership, co-ordination and oversight.

1. Ministers and political parties to commit to halving hepatitis C related liver cancers and deaths by 2020 and eliminating the virus by 2030
2. The Department of Health to take lead responsibility for an implementation plan to replace the 2004 Action Plan for Hepatitis C and ensure a coordinated and effective approach to testing, treating and curing people with the condition and the prevention of new infections
3. A Hepatitis C Elimination Group, reporting formally to Ministers, to be established to co-ordinate the work of the relevant health organisations in improving services, comprising the relevant statutory and non-statutory organisations and patient, clinical and local government representatives
4. Testing for hepatitis C and other blood-borne viruses to be provided in a range of healthcare settings to maximise coverage, working to nationally-agreed performance standards as part of structured care pathways
5. Commissioners to ensure that, as a core part of contracts, service providers collect and report data on their hepatitis C outcomes to standards set by Public Health England
6. NHS England's specialised commissioners to ensure the availability of services and NICE-approved treatments for all patients diagnosed with hepatitis C in line with international guidelines
7. Industry to ensure that new therapies are priced to meet NICE criteria for cost-effectiveness for the whole hepatitis C patient population
8. Commissioners to work proactively with voluntary sector groups providing advice and support to patients with hepatitis C and to develop prevention strategies targeted at people at risk of contracting the virus

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About hepatitis C

- Hepatitis C is an infectious disease which is sometimes known as the 'silent killer' as it can persist undetected for years.[1]
- Left untreated, hepatitis C can lead to cirrhosis, liver cancer and death but treatments are available that can cure the disease in the majority of cases.[2]
- Around 160,000 people are chronically infected with hepatitis C in England.
- It is estimated that around 50% of these remain undiagnosed and susceptible to the development of long term complications.[3]
- The burden of chronic hepatitis C is substantial and still growing, as people who contracted HCV many years ago begin to develop long term complications of untreated chronic hepatitis C.[4] [5]
- This presents an increasing challenge to the healthcare community, as well as putting pressure on limited healthcare resources.
- Hepatitis C is a condition of inequalities. In England, it disproportionately affects marginalised groups, including intravenous drug users, prisoners and immigrant populations (often due to inadequate sterilisation of medical equipment).[6]
- A significant minority of people with hepatitis C contracted the virus via NHS treatment with contaminated blood products.[7]

Why is action needed now?

Hepatitis C is the third most common risk factor in liver disease[8] which is the only one of the five "big killers" in the UK where mortality is rising.[9] Within this category, deaths from hepatitis C are rising faster than any other category, more than quadrupling since 1996.[10] [11]

Yet with the right diagnosis and treatment, hepatitis C is curable.[12] Research from the London Joint Working Group found it was cheaper to treat chronic HCV than to allow the disease to progress, and that treating just 10% of those people with hepatitis C could save £200 million in London alone.[13] However, at present only 3% of those chronically infected[14] receive treatment each year.[15]

Illustrative of the failure to tackle hepatitis C effectively, the number of hospital admissions for liver cancer and end stage liver disease in England has increased steadily over time. Without earlier identification and more treatment, the burden of end stage liver disease, liver cancer and liver disease mortality from hepatitis C will continue to grow for at least the next 20 years.[16]

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Current state of services

The current state of hepatitis C services in England is unacceptable. Too often, examples of good practice are restricted to specific areas or centres of excellence. This can mean that access to good hepatitis C services can be dependent on where people with hepatitis C are living, as well as on how proactively different parts of the UK approach testing and referral of patients to treatment.

Limited data collection makes it hard to quantify the current state of hepatitis C services but from the information that is available and anecdotal evidence gathered through our day-to-day activities, we know that there is significant scope for improvement across awareness, testing, treatment and care and support.

Awareness: Research by The Hepatitis C Trust found that only 30% of local authorities have awareness campaigns in place on hepatitis C and less than half have measures to prevent hepatitis C transmission among at risk groups.[17]

Testing: Data from Public Health England shows that the rate of testing for hepatitis C has stabilised since 2008. The report states this may be because the 'easy-to-reach' individuals have now been tested.[18] This means that once again, those on the periphery of society, people who are homeless, injecting drug users or from immigrant populations are missing out on the potential to receive a diagnosis and receive care, support and treatment for their hepatitis C.

Treatment: Treatment rates in England have been very low. Just 3% of people diagnosed with hepatitis C received treatment in the last year for which data are available.[19] On an international level, the UK was ranked 13th out of 14 comparable countries for the use of hepatitis C treatments in 2011.[20]

Care and support: Many people with hepatitis C are lost to follow up which means that their condition may be deteriorating but there is no healthcare team to monitor this and to advise on the best course of action if there is any sudden change in disease progression.

Prisons: There is still variation in the services on offer to people with hepatitis C in prisons. Only just over half of prisons have an active engagement programme on blood borne viruses with new arrivals yet as many as 19% of the prison population may have had some previous exposure to hepatitis C.[21] Approaches to treatment also vary greatly, many prisons do not have measures in place to stop or delay transfer of patients who are undergoing treatment.[22]

Barriers to change

Continued underperformance in hepatitis C has occurred for a number of reasons:

Policy failures: The 2004 *Hepatitis C Action Plan* acknowledged the low profile of hepatitis C.[23] However, the commitments made in the Action Plan were vague and fell short of the ambition required to drive improvements in services on the ground. Moreover, it failed to establish any measurable targets, benchmarks or procedures to appraise proper implementation. Subsequent development of a National Liver Strategy was then halted in late 2013.[24]

Commissioning changes: Hepatitis C commissioning responsibilities are now shared across NHS England, CCGs, Public Health England and Offender Health. There is confusion within the NHS commissioning community and elsewhere about who commissions different aspects of services. Anecdotal evidence suggests that the ongoing confusion is contributing to a reluctance to refer and to treat patients.

Pressures on the health service: The NHS is facing unprecedented financial pressures, with an estimated funding gap of around £30 billion between 2013/14 and 2020/21 predicted.[25] The opportunity to dramatically improve outcomes in hepatitis C must not be lost despite the difficult financial context.

At-risk groups: Hepatitis C is a challenging condition to identify and treat because of the people that it affects. The majority of people with hepatitis C are injecting drug users, many of whom live haphazard lifestyles. Migrant communities are often less likely to access healthcare[26] and many people with the virus may have contracted it a number of decades ago and would have no reason to suspect they might have the condition.

What could be achieved?

Increasing diagnosis and treatment would reduce the burden on the health service, save money and most importantly, save more lives.

A recent study showed that the largest reduction in hepatitis C related morbidity and mortality will occur when increased treatment rates are combined with more effective treatments, generally in combination with increased diagnosis. It found that with a treatment rate of approximately 10% it is possible to achieve elimination of hepatitis C by 2030.[27] Modelling work recently undertaken by Public Health England suggested that the benefits of increased rates of treatment would be maximised if implemented quickly and that reduction of the incidence of hepatitis C to around 500 by 2030 is possible.[28]

The elimination of hepatitis C as a public health threat is achievable. With concerted action, it will be possible to eliminate the virus from the UK-born population by 2030.

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ABOUT THE HEPATITIS C COALITION

The UK Hepatitis C Coalition was established at the end of 2013 to bring together a range of expertise on hepatitis C and related services. The Coalition includes patient groups, clinicians and others with an interest in hepatitis C who share the objective of securing coordinated action to reduce deaths from hepatitis C and turn the tide on liver disease mortality in the UK. The Coalition is run with funding from Gilead Sciences Ltd.

Members

The Coalition is Chaired by Professor Mark Thursz, Consultant Hepatologist at St Mary's Hospital. Its members are:

Observers

To complement the Coalition's membership, a number of experts with an interest in hepatitis C services have agreed to be associated with the Coalition as observers. They receive the Coalition's meeting papers and are able to attend meetings to contribute their expertise. However, the Coalition's policy positions and priorities are determined by its core membership.

http://www.hepc-coalition.uk/
Please contact hepc@jmcinform.com with any queries.

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Coalition governance and ways of working

Further details about the Coalition's governance and ways of working are available on its website. The secretariat to the Coalition is provided by JMC Partners LLP. Gilead Sciences Ltd provides financial support to the Coalition by meeting the costs of JMC as the group's secretariat. Gilead Sciences Ltd is a member of the Coalition and subject to the same terms as other members.

This manifesto has been drafted in consultation with all members and approved by the group as a whole. A further compendium of information is available on the Coalition's website, including further evidence and case studies from people with hepatitis C, clinicians and other experts.

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